THE DEVELOPMENTAL DISABILITY SECTION PRESENTS

TRAINING CURRICULUM ELEMENTS FOR PERSON CENTERED PLANNING

DIVISION OF MENTAL HEALTH,
DEVELOPMENTAL DISABILITIES,
SUBSTANCE ABUSE SERVICES
DEPARTMENT OF HEALTH AND
HUMAN SERVICES
(R) April 2001

PERSON CENTERED PLANNING
TRAINING CURRICULUM: ELEMENTS FOR PERSON CENTERED PLANNING
TABLE OF CONTENTS

Attachments:

Overheads/Handouts
    1. Introduction
    2. Listen…In Order To Hear
    3. Program Centered versus Person Centered
    4. Week-at-a-Glance
    5. Where We've Been
    6. Person Centered Language

Form 1 (Required): CAP-MR/DD Elements for Person Centered Planning

Form 2 (Optional): Documentation of Demonstration of Competencies

Form 3 (Optional): Checklist for Agencies for Assessing Presence of Elements Which Support Outcomes

Form 4 Rephrasing: Instructor's 'Cheat Sheet" for Overhead 7

Article: *Person Centered Planning, Should We Do It With Everyone*

CORE ELEMENTS FOR PERSON CENTERED PLANNING

❑ Understand the importance of language that demonstrates respect, shared control, and use of "person first" language.

❑ Understand the basic philosophy of person and family centered planning.

❑ Understand the difference between traditional planning methods and use of the person centered model.

❑ Understand the methods for gathering information about the person.

❑ Understand support staff roles and responsibilities in planning and implementing a plan with a person or with a family.

❑ Understand that people change, therefore their plan changes.

PERSON CENTERED PLANNING
AGENDA FOR
CORE CURRICULUM
ELEMENTS FOR PERSON CENTERED PLANNING

Introduction
 Read "Preface"
 Overhead 1: Introduction

Ice-Breaker
 Activity 1: Ice-Breaker
 Overhead 2: Listen…In Order To Hear

Where We've Been, Where We're Going
 Bridging
 Overhead 3: Program Centered versus Person Centered
 Activity 2: Week-at-a-Glance
 Overhead 4: Week-at-a-Glance
 Overhead 5: Where We've Been…

The Power of Language
 Bridging
 Overhead 6 (2 pages): Person Centered Language
 Activity 3: Rephrasing
 Overhead 7: Rephrasing
 Overhead 8: The Reputation Trap…A Real Bear of a Trap
 Discussion
 Overhead 9: The Power of Our Language

Getting to Know what People Value
 Bridging
 Activity 4: Morning Rituals
 Discussion
 Activity 5: What Makes Sense
 Discussion
 Overhead 10: What Makes Sense…What Doesn't Make Sense
 Activity 6: People Map
 Overhead 11: People Map
 Discussion

Planning
 Bridging

Overhead 12: Balance

Discussion

Activity 7: Driving Me Crazy

Overhead 13: Driving Me Crazy
Discussion
Overhead 14: A Shared Walk

Summary

Bridging
Activity 8: Change
Overhead 15 (2 pages): Change
Overhead 16 (3 pages): John
Discussion

Directions for Using Curriculum

1. This core curriculum can be taught in a portion of one day or it can be taught in several segments. The segments, each stressing a core element, are

    1.1. Ice-Breaker
    1.2. Where We've Been, Where We're Going
    1.3. The Power of Language
    1.4. Getting to Know What People Value
    1.5. Planning
    1.6. Summary

2. The instructor makes overheads from the Attachments, section 'Overheads/Handouts'. The instructor also makes packets of the handouts (1 – 16) for each participant, using the materials in the section 'Overheads/Handouts'.

3. The overheads are the same as the handouts and are numbered as they are presented. As well, within the text of the curriculum, if an overhead is referenced, it is also printed within the curriculum following the flow of the presentation, unless otherwise noted. There is a cue for the instructor when an overhead is to be used – (Chart or Overhead & Handout), (Chart/Overhead & Handout). The participants should already have their own handouts when class begins. Both a chart and overhead do not have to be used at the same time. (See 4 for use of charts.)

4. The instructor can choose to use a chart instead of an overhead. The overheads have the information that will need to be transferred to a chart, if a chart is used. The instructor may choose to use a combination of a chart and an overhead.

5. Each section within the Curriculum ends with "Note". Here, the instructor will be able to determine if the activities can be done with only one participant or if substitute activities are recommended.

6. Equipment that is needed includes an overhead projector and an easel for a chart.

7. General materials that are needed include (if different materials are needed for a *specific* segment of the curriculum, it will be listed in the 'Materials' section preceding the activity – see Ice-Breaker)
    ➢ 3 sheets of chart paper per participant
    ➢ one or more water-based magic markers per participant (no yellow)
    ➢ handouts 1 – 16 (overheads)
    ➢ masking tape

PREFACE

As seen through the eyes of a parent....

"Ever since my child was thought to be different at two years old, we have been making 'plans' for him. While they would ask about my son's strengths, likes and dislikes, very little time was spent on these things. Mainly, we spent time trying to fix the brokenness of my son. When I learned about person centered planning, especially Essential Lifestyle Planning and Circles of Friends, all I ever believed in was confirmed. I knew there was a better way to look at my son's strengths and a way to plan a life for him and my family based on his gifts and talents. We now look at everything, not just those things that can be funded. I am very excited and looking forward to truly building a normal, well-rounded life for my son just like any other parent."

**PERSON CENTERED PLANNING
TRAINING CURRICULUM
ELEMENTS FOR PERSON CENTERED PLANNING**

Introduction (Chart or Overhead 1 & Handout)

The development of organized practices for person centered planning began around 21 years ago. This term refers to a family of approaches, which focus upon the person who needs supports, using methods of organizing and guiding community change in alliance with people with disabilities and their families and friends.[1] There are 5 different, recognized approaches to using this type of planning. They are Individual Service Design, Personal Futures Planning, Essential Lifestyle Planning, MAPS – using Circles of support to address the day to day problem solving and to keep the plan moving forward, and PATH. The common foundation of beliefs represented by these approaches provides both a map and a challenge for moving forward, as an individual with a disability, as a friend or family member, as an individual supporting someone with a disability, as an agency and as a system. These beliefs are

- ✓ **The person is at the focus of planning and those who love the person are the primary authorities on the person's life direction[2]**
- ✓ **The purpose of this type of planning is the learning that occurs when the person and those who know and like him best share in making things happen, by trying new things together, and learning from them**
- ✓ **This type of planning aims to assist the person to be a valued part of community life, not segregated, but involved with others who do not have recognized disabilities**
- ✓ **In order to create community change to improve a person's chance for a better future, the use of person centered planning should be a challenge for change for human service policies and for agencies in the way they regard people with disabilities – where practices exist that separate people and encourage controlling relationships. This type of planning requires that we work together**
- ✓ **When there is an honest effort to use this approach, it comes from a respect for the dignity and wholeness of the person**
- ✓ **Because this process engages such powerful emotional and ethical issues, using this approach calls for the person working with family, friends, agency representatives, and system staff to maintain a sustained search for effective ways to deal with difficult barriers and conflicting demands.**

---

[1] O'Brien & Lovett, 1992
[2] O'Brien & Lovett, 1992

This approach is not a technique to develop a formal plan. It's much more exciting. And in using this approach, the boring routines of annual planning meetings explode into a real walk with a person, who happens to have a disability.

I. Ice-Breaker[3]

Purpose
To introduce the concept of
✓ hearing what a person is asking;
✓ listening to the person;
✓ and of not assuming.

Materials Needed
Overhead projector
Overhead 2
Chart
Chart stand
Handout #2
Lego's
Tape
Magic Markers
Glue
Paper
Lincoln Logs
Dominoes
Stacking blocks

Instructor Directions
Activity 1: Ice-Breaker (20 minutes)

Break participants into groups of 4 or 5 individuals (per group)*

---

[3] Contributed by Debbie Caulder
[4] Smull & Allen, 1998
[5] Kingsbury,1996
[6] Adapted by Beth Phillips & Debbie Caulder from Michael Smull's Reputation Exercise, 2001
[7] Smull & Allen, 1998
[8] Smull & Allen 1998
[9] Smull & Allen, 1998
[10] As used by NC Circles
[11] Smull & Allen, 1998
[12] Smull & Allen, 1998
[13] Smull & Allen, 1998
[14] Smull & Allen, 1998
[15] Smull, 1996
[16] Smull, 1996
[17] Smull, 1996

Give each group a bag – 1 group a bag of Lego's (small or large) and a domino; 1 group a bag of Lincoln Logs and a domino; 1 group a bag of paper, tape, magic markers, glue, and a domino; 1 group a bag of wooden stacking blocks and a domino

Ask all participants to **"Make me something"**

Say, "If anybody has questions, please raise your hand and I will come to your group." Instructor can answer questions, but does not volunteer information. After each group has finished have them show the rest of the group what they made

Ask each group:
- ➢ **How did you decide to make what you made?**
- ➢ **Did you all work together or did only a few of you do this?**
- ➢ **What process did you use?**
- ➢ **What did you do with the domino?**

(*Make sure each group gets good recognition for efforts*)

(Note to Instructor: When doing this part of the activity be careful not to embarrass anyone; "overact" so participants do not feel targeted.) **Ask** participants if they remember what you asked them to do (Make me something)

Ask/Comment
- ➢ **How many groups made <u>me</u> something?**
- ➢ **What is this workshop called (Person Centered Planning)**
- ➢ **Who is the person? (instructor)**
- ➢ **No one asked me what I wanted**
- ➢ **Ask if anyone knows why a domino was included**
- ➢ **The domino: point out that when someone different comes into our lives we try to find a place for that person or we leave the person out <u>because</u> he/she is different and we don't try to discover the gifts that the person may bring to our lives.**

Instructor uses the following example to stress how each of us wants to be heard. (Can substitute other examples that have meaning to the instructor).

- ➢ You are in the emergency room with your husband. He has had a very bad fall, has broken ribs and a vertebra and hit his head. You have provided information that your husband has seizures. The neurologist, on call, examines him and asks what seizure medication he is taking. You report, Phenobarbital. The neurologist says that he should be on Dilantin

and Phenobarbital. You explain that he had a very bad reaction to the Dilantin, that the Phenobarbital has been the only stabilizing drug for the seizures. Before you go home that evening, you check to make sure your husband has the Phenobarbital and find there are no orders for seizure medication. The nurse phones the doctor. His orders read, "Phenobarbital and Dilantin".

Points (Chart or Overhead 2 & Handout)
➢ **Hear what a person is asking/saying, either with language or with behavior**
➢ **Ask questions to find out what a person really wants**
➢ **Let the person build the picture in your mind of what he/she wants – don't already have a picture in your mind that predetermines what the person wants**
➢ **If the person doesn't use language to communicate, what is his/her behavior asking of you**
➢ **Look for the gifts or contributions to the community that people bring, who are different**

Summary
Each of us wants others to really listen to us, to understand what we are saying or asking. If others don't understand what we want, we want a person or persons to ask questions. We feel valued when people take the time to listen and ask questions.

---

*Note
The above activity can be used with just one person or with a large group. A variation of this activity is "Make me a day's menu". You follow the same procedures, make the same points. For materials, you need paper and pencil/pen, or you can use chart paper and magic markers, have participant(s) put the paper on the wall and write the menu there. Participants can work alone or in small groups.

II. Where We've Been, Where We're Going

Element
Understand traditional planning methods and use of the person centered model

Materials Needed
Overhead projector
Overheads 3, 4, 5
Handouts #3, 4, 5
Chart paper
Water based magic markers

Masking tape
Chart stand

Bridging
Instructor introduces the next section by saying that in addition to listening & hearing what a person is telling us, we need to look at/see what a person's lifestyle is telling us.

Instructor Directions
Instructor gives each participant 3 sheets of chart paper and has participants select wall space to put up the three charts. (*If teaching this curriculum in segments, will only need 1 sheet of chart paper per participant.*) Each chart should be visible. Once the charts are up, participants **put their names on each sheet of chart paper** and then return to their seats.

Instructor discusses the changes made during the past 21 years using the overhead below. **Instructor tells** participants that we, as providers of supports and services, are in the process of moving from program centered services to person centered services. **Instructor discusses** each type of change below **(Chart/Overhead 3 & Handout[4])**.

PROGRAM CENTERED	PERSON CENTERED
Planning <u>For</u>	**Planning <u>With</u>**
Talking about you	**Talking with you**
Doing things to you	**Doing things with you**
Following your program	**Having a life**
You live where you "fit"	**You choose with whom and where you live**
We are in control	**We share control**
Starting with what's wrong	**Starting with what is important**
Issues of health and safety dictate where you live	**Issues of health & safety are addressed where you want to live**
We "let", "allow", and "place"	**We "support", "assist"**
We set your goals	**We suggest, you**

decide

You learn the "next" developmental step

We figure out together what you want to get what you need

Activity 2: Week-at-a-Glance (15 minutes)

Point of activity: to get a glimpse of how far we've come in making person centeredness a reality; to see if the person receiving supports is a member of the community or still remains a member of the agency community (workshop, day program, events for those with disabilities, etc.)

Instructor asks the participants to go to one of the charts and draw a line down the center of one of the 3 sheets. On one side, participants are to list the various activities in which they may be involved the upcoming week. The following example (**Chart/Overhead 4 & Handout**), or an example of the instructor's week, can be used to show participants what they need to do.

Monday: work, take son to dentist
Tuesday: work, son's soccer practice, choir practice
Wednesday: off/work, doctor, grocery store
Thursday: work, take son to soccer game
Friday: work, home
Saturday: work, soccer practice
Sunday: church, family reunion

After participants have completed their week-at-a-glance, **ask** different participants to tell the others what they will be doing, using their chart. **Next,** ask the participants to think of someone with whom they are providing supports. On the other side of the chart, have them then write an example of a typical week for that person. **After** this is done, **ask** several participants to read the schedule of the person they support. Participants can return to seats for discussion. **Discuss** the similarities of the schedules.   **Discuss** the differences. **Instructor reviews** the **points** below (**Chart/Overhead 5 & Handout**) and then the summary.

Points
- ✓ **Moving from a program centered approach to a person centered approach is more than using new language**
- ✓ **We, as providers of supports and services for individuals with disabilities, are in the process of learning how to respect that the person or family should be setting the course of our actions**
- ✓ **Person centered planning is a commitment to break barriers for**

individuals to be a part of community life; to change policies; to change practices; to change the way we think; to give up control; to actively listen; to demonstrate respect for the person or family in working with either to support the vision of the person, of the family for their child

Summary
Many staff of agencies who provide supports for individuals with disabilities use person centered language. But practices have to change and become more flexible in order to support a person centered process. There is still a need to move away from a **focus** on the development of skills in small steps, finding out what is wrong with a person so a goal can be developed, writing behavior plans for behaviors that most individuals have the privilege of experiencing (being "non-compliant", "eloping", being "verbally aggressive"). It is hard to give up control and learn how to really share the control. We, as members of agencies, are reluctant to give up comfortable processes and methods of doing things.

Note
This activity in this section can be done with one person.

III. The Power of Language[5]

Element
Understand the importance of language that demonstrates respect, shared control, and use of "person first" language

Materials Needed
Overhead projector
Overheads 6, 7, 8, 9
Handouts #6, 7, 8, 9
Chart
Chart stand
Prepare, ahead of class, one chart sheet with questions 1 – 10, page 9
Pencil/pen per participant

Bridging
Instructor introduces the next section: As previously discussed, many people are using person centered language even though practices of supporting individuals have not changed. But often, as the words are used, they begin to make sense and we can begin to see how powerful a tool our language is.

Instructor Directions

Instructor provides the following overview (Chart/Overhead 6 & Handout):

- ✓ Language which communicates information about a person, in easily understood, non-clinical, non-"disability speak" words

- ✓ Is the use of plain, simple language

- ✓ Gets rid of words that only human service and medical personnel know

  - ▪ Walks vs. Ambulates
  - ▪ Doesn't talk using words/talks <u>vs</u>. Non-verbal or verbal
  - ▪ Paralyzed on the right side <u>vs</u>. Has right hemiparesis

These words belong in a medical setting, such as a hospital; not in people's homes and in their lives within the community

- ✓ Language which focuses on the person, and not the clinical labels and reputation

  - ▪ Gets loud when he is angry <u>vs</u>. verbally aggressive
  - ▪ Decides he doesn't want to do things sometimes <u>vs</u>. non-compliant
  - ▪ Is interested in other things <u>vs</u>. off-task

- ✓ Language which is always PEOPLE FIRST
  - ▪ People with disabilities
  - ▪ A person with mental illness
  - ▪ A young man with autism
  - ▪ A woman with a brain injury

- ✓ Language which is respectful of the person and any issues present

- ✓ Language which does not group people by their labels
  - ▪ The retarded
  - ▪ The disabled

<u>**Activity 3**</u>: **Rephrasing (10 minutes) (Chart/Overhead 7)**
Point of activity: to have participants begin to think through and apply what they have just heard.

The **Instructor asks** the participants to take a moment to look at the handout (**Chart or Overhead 7**) titled, "Rephrasing". (This can be done by breaking participants into small groups or calling on participants, individually.) **Calling on**

participants, the **Instructor asks** the group representative/individual to reword a sentence, until all sentences have been reworded.

1. Mary is a 24 year old moderately retarded Downs female
2. Lisa goes off task at her vocational placement
3. Robert is an elderly stroke victim
4. Let Mary walk to the park by herself
5. Joe is a quad and total care client
6. Sue is non-compliant with her personal hygiene program
7. Staff did Ruth's meds and put her to bed
8. Darryl should be allowed time alone when he needs it
9. I fed Grace and gave her a bath
10. Mother tube-feeds at 8:00
11. When instructed to do so, John will independently vacuum his floor for 5 consecutive sessions.
12. When instructed to do so, Beth will brush her teeth with 100% independence for 5 consecutive sessions by 01-31-02.

The Instructor moves directly into looking at reputations with the following exercise with questions listed on chart paper.[6]

1. **How many of you have ever just had to get away for a while?**
2. **How many of you have avoided work – either at home or at work?**
3. **How many of you will be doing something at home and start doing something else before you have finished what was started. Or you start talking to someone at work when you are supposed to be writing notes?**
4. **How many of you have ever lost your temper and argued with someone?**
5. **How many of you have ever had a drink?**
6. **How many of you have ever broken anything in anger – go back to your childhood?**
7. **How many of you have ever hit someone or bitten someone in anger – go back to your childhood?**
8. **How many of you have ever failed to stop at a stop sign or have exceeded the speed limit?**
9. **How many of you have ever, just gone off your diet for a while – having just that one piece of cake or that melted chocolate over ice cream?**
10. **How many of you have ever deliberately set fire to a building, just to enjoy the flames and the chaos?**

The Instructor gets a hand count for each of the questions and writes the hand-count on the chart. Then the Instructor shows Overhead 8

(Text of overhead not included below).

Discussion:
➢ **What should be the consequence for each of these offences? (Instructor goes through each one)**
➢ **Which offence is one for which we need more information if someone says that they did it?**
➢ **How many of us earn these labels daily? Weekly?**
➢ **Are we on behavior programs?**
➢ **If behavior programs work – why aren't we passing laws to put more offenders on them?**
➢ **Why do people with developmental disabilities have to have behavior programs for doing the same thing that people without disabilities do frequently?**

The Instructor reviews the following points (Chart/Overhead 9 & Handout)
Points
✓ **Our language has the ability to place and/or shift control.**

✓ **Person centered language is language which says, "the person is in control", even if the person needs total assistance with all aspects of his/her life.**

✓ **We need to always ask, "who's in charge?" Changing our language shifts the responsibility and means we SHARE it with the person receiving supports…as in "I helped Jane get dressed" (I shared this with Jane) instead of "I dressed Jane" (I am in charge).**

✓ **Changing our language means we move from a hierarchy of "staff and client" (which equals powerful and not powerful) to "person to person"…equity and respect**

✓ **What people do to earn a reputation is often a symptom of a problem. We need to brainstorm around ways we can provide supports to make the problem go away – not assign a behavior program to deal with the symptoms**.

Summary
Consciously changing our language out of respect for others takes time. With time comes greater insight into the need to change. The benefit is to us.

Note
The exercises described in Section III can be done with one person or a group of

participants

IV. Getting to Know what People Value

Element
Understand the methods for gathering information about the person

Materials Needed
Overhead projector
Overheads 10, 11
Handouts #10, 11
Chart stand
Chart paper
Masking tape
Water color magic markers
Instructor's morning routine already prepared on chart paper (or can make an overhead)

Bridging
Instructor says, "As we change our language, our values begin to change. Let's look at some of the things that we value."

Activity 4: Morning Rituals[7] (25 minutes)
Instructor Directions
Instructor introduces the morning ritual by **asking some of the following questions** and having the participant(s) respond:
   ➢ **How many of you are morning people?**
   ➢ **How many spring out of bed with a smile on your face and a song on your lips?**
   ➢ **How many of you crawl from the bed and refuse to have words with anyone until your caffeine blood level rises?**
   ➢ **What would the non-morning people do if they were awakened and supported through their morning by the cheerful, morning people?**
   ➢ **How many of you sleep until the last possible minute?**
   ➢ **How would you feel if you were awakened an hour and a half earlier than usual, hustled thorough your routine and then parked in front of a TV set until it was time to leave?**
   ➢ **How would you express your feelings?**
   ➢ **How many of you shower in the morning?**
   ➢ **Would you still shower in the morning if you had showered the night before? For those who answered yes, showering is about more that getting clean - discuss this.**

> **When do you brush your teeth?**
> > **before the shower or bath?**
> > **during the shower?**
> > **after the shower but before leaving the bathroom?**
> > **after breakfast?**
> > **more than once – both before and after breakfast?**
> **How would you feel if I made you change to another part of the morning – earlier or later or only once?**

Instructor: review your own morning routine as a sample for the group. Have it on flip chart paper or as an overhead.

Now **tell** the group that they will be writing their own morning routine. They will use the second of the three pieces of chart paper. As they write their ritual they should use as much detail as they are willing to share. Tell them that the other people in the group will be reading their ritual. *They should edit **out any excretory or sexual parts of their rituals.*** If people say they do not have a ritual or that it is often different, ask them to write up either their nightly routine or their Sunday morning routine.

Instructor walks around and looks at participants' routines. Instructor can press for detail but not press so hard that people who are very private feel embarrassed or humiliated. Ask people to start with how they wake up - an alarm clock, just wake up, or someone wakes up. If an alarm clock, what time is it set for? Is it set for the real time or have they set the clock ahead? By how much? Do they wake up to a buzzer, music, talk radio? Any snooze alarm hits (mechanical or human)? How many? Then what?
Walk around and encourage people while they are writing their ritual. Ask for more detail where needed and praise people who are doing well. Begin to look for the examples that you will use to start the discussion.

Instructor asks participants to wander around the room and read each other's rituals. Expect people to have a good time, with lots of comments and laughter. Before the excitement has totally died down but after most people have read all of the rituals, ask everyone to stand in front of their own ritual.

Ask the one or two volunteers you have pre-selected to share their ritual.

Now **ask** each person to move to the right (clockwise) three rituals. **Tell them** that this is their new ritual. What is their reaction? **Ask some volunteers** to say what they like the most/dislike the most about their *new* routine.

Point out that we're doing morning rituals but there are many others (day, evening, weekend, birthday holidays, celebrations, death, etc.)

Now *ask* what implications this has for the people we support.
- ➢ **How do you feel if your morning rituals are ignored?**
- ➢ **How much of the rest of the day is affected?**
- ➢ **What would you do to get your ritual back or to express your displeasure at its absence?**
- ➢ **What rituals do you continue that began in childhood?**
- ➢ **What would it do to your behavior/outlook if your rituals were mostly ignored (but occasionally honored) over a period of years?**
- ➢ **Do we know what the individual rituals of the people we support are?**
- ➢ **Do individuals we support follow a set schedule developed by staff?**
- ➢ **What are mornings like in the typical houses were they live?**

Before moving on to the next activity, the Instructor says, "…Imagine. You have had a bad day at work. It didn't help when your partner didn't wake you up when you slept through your alarm clock. You couldn't enjoy your cup of coffee before leaving home – you rushed out of the house. You really messed up at work and then got mad at your boss and said something you regret. All you can think about is going home and saying to your partner, 'I don't want to do the chores planned for this evening. Let's go out for dinner or the movies instead?' You walk in the door. Your partner is in the kitchen. You go up for that reassuring hug. Your partner turns, points to the list on the fridge and says, 'Because you spilled your coffee on the floor this morning, in your rush to get to work, I've added cleaning the kitchen floor to your list of chores for tonight. I'm going out with friends.'"[8]
(The above should be used to lighten up the mood.)

Activity 5: What Makes Sense[9] (25 minutes)
Purpose of exercise
(1) to have participants begin to examine the concept of respect of personal choices
(2) to introduce the concept of perspective about "what makes sense" in peoples lives

The instructor talks about the idea that sometimes events happen in our lives, e.g., a move, a death, sickness, a marriage, a birth, etc., and we can start to live in routines that don't make sense to us.

Instructor asks participants to go to one of their clean sheets of chart paper and **draw** a line down the center of the paper. Next, **draw** a line across the

center of the paper. They are **asked to label** the left side of the paper, "What makes sense about my morning routine, to **labe**l the other side, "What doesn't make sense about my morning routine". They are asked to **use only** the **top half** of the chart paper. Participants are asked to review their morning rituals for "what makes sense", "what doesn't make sense" about their own morning ritual.

Participants fill out the columns, using their own rituals and perspective. **Instructor asks** several participants to talk about what they find makes sense and what doesn't make sense.

Participants are then asked to move back to the routine that "had become their new routine". They are asked to think again about the new routine and "live it" as their own. After participants have "lived " in the other person's routine, they are asked to **complete the bottom half of the paper** noting "what makes sense/what doesn't make sense" about this new routine.

Participants will fill in the bottom half of the existing sheet with "what makes sense/what doesn't make sense about _____'s morning routine from _____'s perspective (using the same two column format).

Using an example from the completed charts (after asking permission to do such), **Instructor asks** the participants to discuss what did and didn't make sense to them. **Instructor** then **leads a discussion** about the **concept of perspective**. **Instructor** also **stresses** the importance of making sure that we remember this point when involved in person centered planning, making sure that we note our perspective but don't impose it on others.[10]

Discussion
Instructor asks the participants, "If you wanted someone to get to know <u>you</u> well
➢ **what questions would you want the person to ask you**
➢ **what would you want them to notice**
➢ **what are the things you would you want the person to do with you**
➢ **what would you want them to value**
➢ **who would you want them to talk to about you"**

Give participants time to think about the questions and then **discuss** the responses

Points (Chart/Overhead 10 & Handout)
Instructor stresses the following points

❖ **Life events, practices or routines that make perfect sense to one person, may make no sense to someone else**

- ❖ **Often, people with disabilities are asked to live someone else's routine because of where they live or who supports them**

- ❖ **People with disabilities are often asked to live a routine for staff convenience**

- ❖ **Other's perspectives can be noted but not imposed on people who are receiving supports**

- ❖ **It makes sense not to isolate a person with a disability, but to identify and involve the people, whom the person cares about, in his life**

Activity 6: People Map (Chart/Overhead 11 & Handout) (10 minutes)
Purpose of Activity: to identify those people that are important to a person.

The Instructor talks about the People Map[11]. **Instructor explains** that the person is placed in the inner circle. The second circle, closest to the inner circle, represents those who are closest to the person – at home, at work, within the family, within friends. The outer circle represents those that the person wants in his or her life, but are those, with whom the person has a more casual relationship. The **Instructor asks** the participants to think about their own lives and **to complete** the Map for themselves. **After** the participants have completed the map, the **Instructor asks** the following questions.

Discussion
➢ **What was easy/hard about that activity?**
➢ **How do you find out who is important to the person you support?**
➢ **How do you find out what role the person wants them to play in his/her life?**
➢ **How do you bring this information to the planning meeting?**

Summary
Whether the people and the things that are important in everyday life are present or absent play a role in determining the quality of life for each of us. We all want those closest to us involved in our lives. We all want our rituals and routines; but we want our own, not someone else's. We all need to be listened to and to have some control if we are to get what is important to us. Control is never absolute; it always has limits. Compromise is the norm but choosing where to compromise is essential.[12] When we disagree with another person's perspective, generally we need to see the situation from the other person's viewpoint before taking an action. This is especially important when we are providing supports for someone. We need to try to see the world through that person's eyes.

> **Note**
> Though some of the impact can be lost, the previous activities can be done with only one participant. The instructor needs to take a more active role, however, with Rituals. The instructor will need to display his/her Rituals on chart paper and participate in What Makes Sense so that there can be an exchange of information about "my perspective" and "other's perspectives".

V. Planning

Note: For the next two sections, Planning and Summary, the focus is learning about a person who needs multiple supports. Even if a person receives supports 24 hours a day, the person has rights that should be respected, one of which is privacy. Respecting the person's right to privacy, we work with the person to determine wants and needs. Generally the more support that is provided, the more we seek to learn about and learn from the person. Unless it's an issue of dangerousness, what we learn about a person does not give us the right to exert more control, or to share, without the person's consent, the knowledge we have of that person's life.

Element
Understand support staff roles and responsibilities in planning and implementing a plan with a person or with a family.

Materials Needed
Overhead projector
Overheads 12, 13, 14
Handouts #12, 13, 14
Chart paper for instructor
Chart stand
Magic markers for instructor

Bridging
The Instructor reminds participants that just as it was important to learn about those people that the person wants included within his life, and to bring the information gathered into the planning process, it is also important to recognize all the dimensions of an individual.

Instructor Directions
Instructor shows overhead. **(Chart/Overhead 12 & Handout)**

Discussion
Instructor asks
  ➢ **What are the considerations with cultural issues**
  ➢ **What needs to be considered with spirituality**

> ➤ **What needs to be considered with safety**
> ➤ **What needs to be considered with relationships**
> ➤ **With community life**
> ➤ **With medical health**
> ➤ **With mental health**
> ➤ **With work**
> ➤ **And what is meant by "learning about what is important to the person in these areas"**

After the discussion, **introduce** the next activity by talking about the importance of gathering information (which is an on-going process); gathering only as much information as the person is willing to share (unless there are issues that put others or the person at great risk); with permission, gathering information from those that are involved with the person. **Ask, "Then what?"**

Activity 7: Driving Me Crazy[13] (20 minutes)
Purpose of activity:
1) to help participants understand how a person's plan is a promise and that plans that are developed but not implemented represent a betrayal of trust;
2) to provide an opportunity for participants to see what the effects of being powerless and not listened to would be on their own lives;
3) and to understand that an entire constellation of behaviors and symptoms, including hitting other people, breaking things, withdrawal, and being desperate to please may be a response to years of not being listened to and being powerless.

Instructor starts by asking participants to think about where they live. Then **asks** them:

> ➤ **What behaviors or habits do the people with whom participants live have that irritate them?**
> ➤ **What are things that other people do that make them crazy- for example leaving the toilet seat up or down?**

As people share them, write them down on chart paper. Fill up the page; use different colors of markers to keep them separated. Encourage people to share until the group begins to run out of contributions.

Then the **Instructor asks** the participants to

> ➤ **Imagine you are now living in a place where all of these things happen.**

The **Instructor reads** out some of the items just written on the chart paper as a description of what happens in this place where the participants are all living. (For example, the instructor takes the examples given by the participants and makes a scenario like the one below

➢ one house mate continually smacks gum and eats crushed ice;
➢ another leaves the top off the toothpaste tube with toothpaste left in the sink;
➢ another cuts his toe and fingernails in the living room and doesn't pick up the cut nails;
➢ one plays music so loud that the house vibrates, etc.)

Then the **instructor tells** the participants

> All of these behaviors are present and the behaviors that you thought about but did not share are also present. However, you cannot leave this place, you have to stay. How do you feel and how do you show other people how you feel? Remember the question is how do you feel and not how would other people feel.

The **Instructor** once again **writes responses.** Then the Instructor lets the participants know the rules of this imagined agency.

➢ People who are aggressive get to move, but to someplace where what makes them crazy happens more and where they have even less freedom;

➢ People who runaway are caught and moved to the same place that the aggressive people have moved to, it is a place that is locked;

➢ People who scream, or are non-compliant, get a behavior program where something that is important to them is taken away and they have to earn its return by not screaming, but there is no other change in their setting.

➢ People who are passive get ignored;

➢ People who withdraw get a socialization program run by a staff person who is particularly irritating.

➢ People who try to please get praised but still have to tolerate the behaviors that drive them crazy.

The **Instructor** now **tells** the participants:
> It is now a year later and nothing has changed. The behaviors that drive you crazy are still present. No one has acted on your distress except as was just described. How do you feel and how do you behave? What are you doing? Again, remember the question is how you feel and not how other people would feel.

Once again the **Instructor writes** down the responses **and applies** the additional clarification to the rules.

➢ Severe depression will get medication.
➢ Self-injury a restrictive program.
➢ Physical illness will get medical treatment.
➢ The general rule is that this agency will respond to symptoms but not causes.

Then the **Instructor tells** the participants:

> It is now 5 years later. The behaviors that make you crazy are still going on. But now a QDDP planner comes and does a person centered plan with you. This person is truly gifted at listening and hears what you are saying with words and behaviors. The QDDP planner hears your distress and captures it on paper. The plan is reviewed with you and you discover that it is not only says just what makes you crazy but also says what needs to change so that these behaviors will no longer be part of your life. After this remarkable experience, the QDDP planner leaves, giving the plan to the QDDP in the agency where you live. The agency QDDP says: *"Just what I need for the licensure survey which is due next month."* But nothing really changes, everything stays the way it was. Now how do you feel and how do you behave?

The **Instructor writes** down the responses and reads them back to the participants. The Instructor needs to emphasize the themes in how people feel.

The **Instructor tells** the participants:

> This is a place like those found in the soap operas. The first QDDP planner was actually the evil twin of the real QDDP. The real QDDP was told she could implement the plan and says- Finally, now I have permission to do what I always wanted. The QDDP is eager to do good plans and the staff is ready to implement them. What will it take for you to trust them?

The **Instructor writes** down the responses **and** goes over what people share _from the perspective of the people that we support_.

(Answers should include such items as:
Time will only show if you are being honest
You'll have to show me that you are listening
It'll be a fresh start
Don't know - you so effectively destroyed my trust that I just don't know.)

The **Instructor points out (Chart/Overhead 13 & Handout)**[14]

➢ **Helping to develop a good plan, based upon what the person wants his/her life to be like, is making a kind of promise and that one is better off not doing any plan than doing a plan where there is no**

commitment to implement what has been learned

➢ Much of the challenging behavior that people in the service system exhibit is explained by this exercise

➢ That we need to be sensitive to the behavior/emotions of the people we support who have had plans done that were not implemented

➢ A person centered plan is a promise - that if developed but not implemented represents a betrayal of trust

➢ An entire constellation of behaviors and symptoms, including hitting other people, breaking things, withdrawal, and being desperate to please, may be a response to years of not being listened to and being powerless

Discussion
Instructor asks the following questions. Have the discussion following each question.
➢ How do you "listen to" behavior
➢ How do you listen to someone who does not use language to communicate
➢ How do you find out what someone wants who does not use language to communicate
➢ How do you bring this information to the planning meeting

Points
Instructor reviews the following points. (Chart/Overhead 14 & Handout)

✓ The plan, itself, is not an outcome[15]

✓ And, the process of planning doesn't change a person's life

✓ What is important is that the person begins to live the type of life he sees for himself

✓ He does this with others (staff person, sister, friend, cousin, neighbor, etc.) around to help with support— they need to be people who know him and like him

✓ (I don't want someone who doesn't like me to make plans for my life)

✓ **Making the plan work involves**
- **listening to the person, "listening" to the person's behavior and trying to   understand what the person wants**
- **seeing the whole person**
- **planning**
- **trying to make the plans work**
- **stopping to see how it's working**
- **if it's not working, seeing what has been missed – trying to listen and understand in a different way**
- **making changes,**
- **working to solve problems that might keep the person from reaching his goals**

Summary

People who know and care about the person for whom the plan is being written should be able to contribute a lot of information. If they are listening, asking questions, seeing the things someone enjoys, doesn't like, things that make the person happy, observing preferred routines, noting the things that the person does well, assisting the person to experience new opportunities (for fun, work, volunteering, meeting people) then this is the information that needs to be a part of the person's plan.

A person may have behaviors that are challenging. Symptoms of those behaviors may be cussing, hitting, breaking things. If those that know the individual say that he is bored, that he is around people he doesn't particularly like, that he likes to work but is currently not working, then solutions need to be developed, as a part of the plan, to address the problem, not the symptoms. He may need another job. He may need opportunities to be away from people he doesn't particularly like – especially if he is with them 24 hours a day (horrors for anyone!).

Plans need to include provisions for cultural needs; e.g., whom the person wants to be around, live with; which neighborhood he finds comfortable; what music and activities he likes. Planning includes looking at a person's spiritual needs as well as relationships.

The person and those planning with him need to look at medical recommendations, dental, speech, occupational therapy, physical therapy, counseling recommendations and consider those recommendations **as we consider** recommendations from our doctors and therapists.

Planning needs to maintain a balance. As we find we are working too hard and need more time for home and fun or have too much time on our hands and need

a meaningful project, we try to put more balance into our lives. So too, should this balance be in the lives of people receiving supports.

Note
Once again, the previous activity can be done with one person. What helps to make it most effective is the input of other participants – hearing about the things that drive them crazy and how they would feel being in the imaginary home. If done with one person, the instructor will need to add his/her input.

VI.   Summary

Element
Understand that people change, therefore their plan changes

Materials Needed
Overhead projector
Overheads 15, 16 (2 transparency pages)
Handouts #15, 16 (3 pages)
Pencils

Bridging
The Instructor stresses the following.
➢ **As previously discussed, planning, to develop a plan, is only one part of person centered planning;**
➢ **Planning is ongoing;**
➢ **The actual document is only as important as it is used and remains current;**
➢ **And, how a person's life changes, with the person demonstrating satisfaction, determines how good we are as implementers of a plan, willing to change direction if it seems we have not listened well.**

<u>**Activity 8**</u>**: Changes (Chart/Overhead 15 & Handout) (20 minutes)**
Instructor Directions
Instructor asks participants to complete Handout 15 (2 pages). **The Instructor stresses** that this information will not be handed in, that it will not be seen by others, if the person does not want to share the information. The information will just be used to generate a later discussion. (Allow about 5 minutes to complete the activity.)

Questions	10 Years Ago	5 Years Ago	This Year
1. Where do you work			
2. Where do you live			
3. Who is your partner			

4. Who are your best friends
5. What kind of car do you have
6. What sport do you play
7. What church do you attend
8. Where do your parents live
9. What do you enjoy doing when you are not working
10. Where are you going on vacation
11. What kind of health do you have
12. What is your main worry
13. What gives you the greatest pleasure
14. What causes you the most pain
15. How many children do you have
16. How many pets do you have
17. Who chooses your doctor
18. Who chooses your dentist
19. Who decides what routines you will follow
20. Who decides what you will do at Christmas? On your birthday? At Thanksgiving?
21. Who decides where you will go on a daily basis
22. Who decides what you will do for fun
23. Who decides with whom you do fun things
24. Who decides what you will eat
25. Who decides what chores you will do
26. Who decides what you will learn
27. Who decides with whom you live

Without discussing activity, have the participants look at handout 16 (3 pages). **[Overhead 16 & Handout** (text of overhead not included below)**])** **Point out** that John is a real person, though John is not his real name. He lived in the institution until 4 years ago, when he moved to a group home near his family. The people with whom he lives are the people that go to the workshop he attends. They are the people he comes home with and goes out with after work. Just recently, after a lot of advocacy, he is able to work part of a day, every other week. The rest of the time, he attends the workshop. 10 years ago, John had a behavior plan for hitting, spitting, cussing, and breaking things. After he got a job, he didn't need a behavior plan. After living in the community without a job, previous negative behaviors began to occur. Now, the agency wants him on a behavior plan because he is hitting, cussing and breaking things – usually his own things.

Put the questions listed under, "Group Discussion" on chart paper prior to doing this activity.

Divide the class into groups of 3 or 4. Within their groups have them discuss

the following questions. Have them list their responses on a piece of chart paper. When all are finished, have the group leader read the group's responses.

Group Discussion
➢ **Have changes occurred within your life?**
➢ **What if I just changed the date on a plan written for you 5 years ago? Would it still apply?**
➢ **What are some of the changes that have occurred within your life? (Responses should be voluntary.)**
➢ **What differences do you see in your life and John's?**
➢ **What similarities do you see in your life and John's?**
➢ **In your current job, what are some things you can do to make John's life more like your own?**

[If it's hard for participants to get started, you may want to assist with using some of the following prompts:
➢ How about changing your own language – asking instead of telling
➢ How about doing things WITH John instead of for him
➢ How about seeing what things and rituals bring John comfort
➢ How about listening to John more
➢ How about asking John questions (if he can't tell you, asking those who have known John in the past, to find out about things he enjoyed, routines he followed, birthday and other holiday rituals he followed)
➢ How about watching and seeing if John is a morning person or a night person and working with him to adjust his schedule?
➢ How about having the members of the house decide what they want to eat, by voting. (Nutritional choices can be given for licensure purposes.)
➢ How about watching John's behavior to see what he is trying to tell you?
➢ How about the members of the home making their own rules?
➢ Has John experienced enough of community life to make _real_ choices about what he wants to do for fun? If not, take him to some of the places that you go to for fun.
➢ Do all members of the home have to go out together for walks, fun, trips to the grocery store?
➢ If there is a staffing problem, then how about the members of the home voting where to go for fun.
➢ Talking with planning team members what John does well, is proud of and what he shows you he wants to learn.
➢ Talking with planning team members about changes John wants in his life
➢ Talking with planning team members what's working/not working for John according to his plan
➢ Talking with planning team members what John likes/doesn't like
➢ Talking with planning team members what John's dreams are for a future**]**

The Instructor needs to point out that we often can make the greatest difference in someone's life just by listening and being with someone – it is up to us to do the best job we can to support someone, within the constraints of the job. The changes that are within our control to make, we can make. For the meetings in which you are a team member, it is important to support what the person wants for his own life, from his perspective. As changes occur within the planning year, it is important to listen to the person, try to understand what the person wants, make the change, and see how the person is doing with the change.[16]

Points
- ✓ **Change is always occurring – it's what some of us strive for and what drives some of us crazy**
- ✓ **When we insulate (overprotect) the life of a person with a disability, we are often the cause of that person not growing, of that person becoming very bored or angry**
- ✓ **For each of us, change involves planning, making choices – good and bad ones, and trying to see how well we are doing with the changes**
- ✓ **A document is a piece of paper**
- ✓ **A written plan is a document**
- ✓ **A document can be added to, to show change**
- ✓ **A written plan is not an outcome**
- ✓ **As the person wants or needs changes to occur, the plan and our actions need to change**
- ✓ **We need to make sure that a person we are supporting won't look back 10 years from now and see a life like John's**

Summary
Within our lives we are always planning, trying, discarding plans and coming up with new plans. Most of the time, unless it's for work, the planning isn't done on paper. It's in our heads, shared with friends or family. When we provide supports to a person, the type of support should be what the person wants. If the person is unable to communicate the type of support wanted, people who really care about the person should try to determine, from the person's perspective, what the supports should be. As the person indicates a need for change, as supporters of that person, we need to find a way to support that change. If we are providing living and day supports for a person, we need to make sure, within our job capability, to assist the person to experience the type of life experiences we are able to experience; the type of choices we have, so the person can try different lifestyles, jobs, fun experiences, learn the responsibilities of those experiences and then indicate what changes he wants in his own life. Person centered planning is a shared walk with a person needing supports. It is a process of listening, planning, trying, discarding plans that don't work and coming up with new plans, always taking the cues from the person. It is a

struggle to maintain a balance. Sometimes, in our desire to provide what's best, we see the person's life only from our own perspective and make things happen that throw the person's life out of balance. Taking our cue from the person's reactions, we can make adjustments, working with the person, to bring about a balance again. It is a joint effort, a shared effort, and an on-going effort. Our job is to make sure that the person has the opportunity to show as much change as our lives have shown in the past 10 years.

Note
Activities within this section can be done with one person. Again, having more individuals being trained together increases the quality of the training. Below, the same exercise is described, but with the intent of using it with one or a few individuals instead of with a group.

Activity 8: Changes (Chart/Overhead 15 & Handout) (20 minutes)
Instructor Directions
Instructor asks participants to complete Handout 15 (2 pages). **The Instructor stresses** that this information will not be handed in, that it will not be seen by others, if the person does not want to share the information. The information will just be used to generate a later discussion. (Allow about 5 minutes to complete the activity.)

Questions	10 Years Ago	5 Years Ago	This Year
1. Where do you work			
1. Where do you live			
2. Who is your partner			
3. Who are your best friends			
4. What kind of car do you have			
5. What sport do you play			
6. What church do you attend			
7. Where do your parents live			
8. What do you enjoy doing when you are not working			
9. Where are you going on vacation			
10. What kind of health do you have			
11. What is your main worry			
12. What gives you the greatest pleasure			
13. What causes you the most pain			
14. How many children do you have			
15. How many pets do you have			
16. Who chooses your doctor			
17. Who chooses your dentist			
18. Who decides what routines you will follow			
19. Who decides what you will do at Christmas? On your birthday? At			

Thanksgiving?
20. Who decides where you will go on a daily basis
21. Who decides what you will do for fun
22. Who decides with whom you do fun things
23. Who decides what you will eat
24. Who decides what chores you will do
25. Who decides what you will learn
26. Who decides with whom you live

Without discussing activity, show **[Overhead 16 & Handout** (text of overhead not included below)**])** overhead 16 (3 pages) and **go through each question**.

 Point out that John is a real person, though John is not his real name. He lived in the institution until 4 years ago, when he moved to a group home near his family. The people with whom he lives are the people that go to the workshop he attends. They are the people he comes home with and goes out with after work. Just recently, after a lot of advocacy, he is able to work part of a day, every other week. The rest of the time, he attends the workshop. 10 years ago, John had a behavior plan for hitting, spitting, cussing, and breaking things. After he got a job, he didn't need a behavior plan. After living in the community without a job, previous negative behaviors began to occur. Now, the agency wants him on a behavior plan because he is hitting, cussing and breaking things – usually his own things.

Discussion
1. **Have changes occurred within your life?**
2. **What if I just changed the date on a plan written for you 5 years ago? Would it still apply?**
3. **What are some of the changes that have occurred within your life? (Responses should be voluntary.)**
4. **What differences do you see in your life and John's?**
5. **What similarities do you see in your life and John's?**

(It's important to lighten things up a bit here so participants do not feel so overwhelmed. The Instructor doesn't want them leaving training feeling that they can't do anything. The Instructor may want to comment, in humor, that John might live in one of the houses in which the participants escaped, in the activity, "Driving Me Crazy".)

6. **In your current job, what are some things you can do to make John's life more like your own?**

[If it's hard for participants to get started, you may want to assist with

using some of the following prompts:

➢ How about changing your own language – asking instead of telling
➢ How about doing things WITH John instead of for him
➢ How about seeing what things and rituals bring John comfort
➢ How about listening to John more
➢ How about asking John questions (if he can't tell you, asking those who have known John in the past, to find out about things he enjoyed, routines he followed, birthday and other holiday rituals he followed)
➢ How about watching and seeing if John is a morning person or a night person and working with him to adjust his schedule?
➢ How about having the members of the house decide what they want to eat, by voting. (Nutritional choices can be given for licensure purposes.)
➢ How about watching John's behavior to see what he is trying to tell you?
➢ How about the members of the home making their own rules?
➢ Has John experienced enough of community life to make *real* choices about what he wants to do for fun? If not, take him to some of the places that you go to for fun.
➢ Do all members of the home have to go out together for walks, fun, trips to the grocery store?
➢ If there is a staffing problem, then how about the members of the home voting where to go for fun.
➢ Talking with planning team members what John does well, is proud of and what he shows you he wants to learn.
➢ Talking with planning team members about changes John wants in his life
➢ Talking with planning team members what's working/not working for John according to his plan
➢ Talking with planning team members what John likes/doesn't like
➢ Talking with planning team members what John's dreams are for a future**]**

The Instructor needs to point out that we often can make the greatest difference in someone's life just by listening and being with someone – it is up to us to do the best job we can to support someone, within the constraints of the job. The changes that are within our control to make, we can make. For the meetings in which you are a team member, it is important to support what the person wants for his own life, from his perspective. As changes occur within the planning year, it is important to listen to the person, try to understand what the person wants, make the change, and see how the person is doing with the change.[17]

REFERENCES

O'Brien, John & Lovett, Herbert. (1992). *Finding a way toward everyday lives. The contribution of person-centered planning.*

Smull, Michael & Allen, Bill. (1999). *Developing first plans! A guide to developing essential lifestyle plans.* Smull & ASA.

Smull, Michael & Allen, Bill. (1998). *Essential lifestyle planning: A trainer's guide For facilitator training.*

RESOURCES

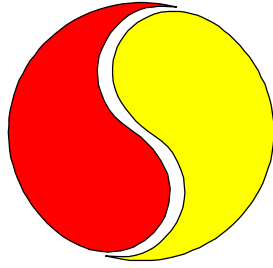O'Brien, John & O'Brien, Connie Lyle, Editors. (1998). *A little book about person Centered planning.* Canada: Inclusion Press.

ACKNOWLEDGEMENTS

ATTACHMENTS
OVERHEADS & HANDOUTS

Introduction

✓ **The person is at the focus of planning and those who love the person are the primary authorities on the direction the person's life will take**

✓ **The purpose of this type of planning is the learning that occurs when the person and those who know and like him best share in making things happen, by trying new things together, and learning from them**

✓ **This type of planning aims to assist the person to be a valued part of community life, not segregated, but involved with others who do not have recognized disabilities**

✓ **In order to create community change to improve a person's chance for a better future, the use of person centered planning should be a challenge for change for human service policies and for agencies in the way they regard people with disabilities – where practices exist that separate people and encourage controlling relationships. This type of planning requires that we work together**

✓ **When there is an honest effort to use this approach, it comes from a respect for the dignity and wholeness of the person**

✓ **Because this process engages such powerful emotional and ethical issues, using this approach calls for the person working with family, friends, agency representatives, system staff to maintain a sustained search for effective ways to deal with difficult barriers and conflicting demands.**

O'Brian & Lovett, 1992
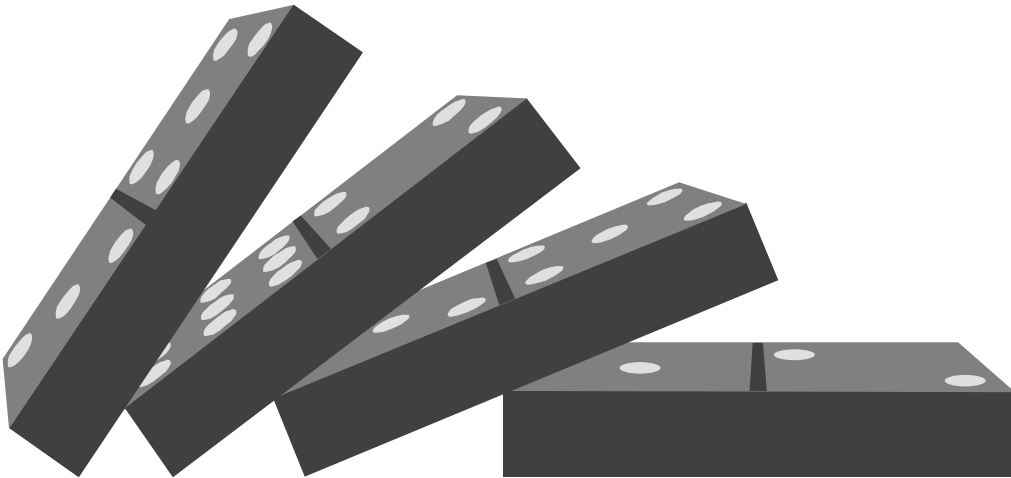
Listen….In Order to Hear

➢ **Hear what a person is asking, either with language or with behavior**

➢ **Ask questions to find out what a person really wants**

➢ **Let the person build the picture in your mind of what he/she wants – don't already have a picture in your mind that predetermines what the person wants**

➢ **If the person doesn't use language to communicate, what is his/her behavior asking of you**

➢ **Look for the gifts that people, who are different, bring**
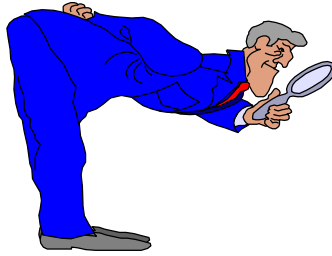
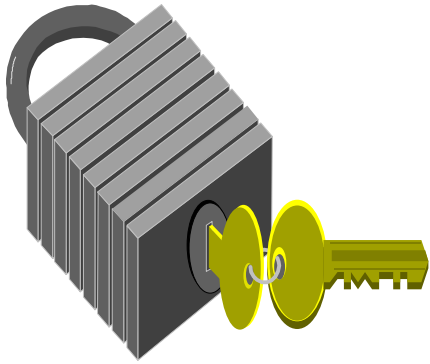| PROGRAM CENTERED	PERSON CENTERED
Planning <u>For</u>	Planning <u>With</u>
Talking about you	Talking with you
Doing things to you	Doing things with you
Following your program	Having a life
You live where you "fit"	You choose with whom and where you live
We are in control	We share control
Starting with what's wrong	Starting with what is important
Issues of health and safety dictate where you live	Issues of health & safety are addressed where you want to live
We "let", "allow", and "place"	We "support", "assist", "help"
We set your goals	We suggest, you decide
You learn the "next" developmental step	We figure out together what you want to get what you need

Smull, 1996

3
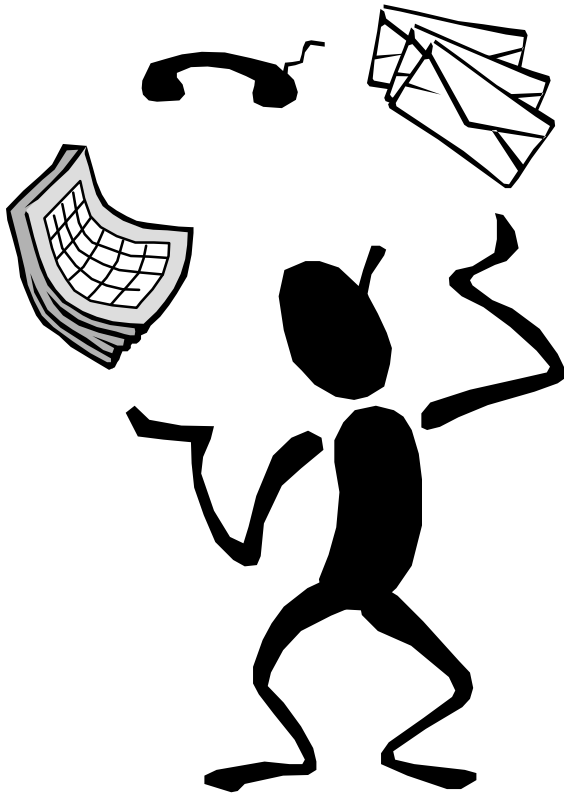
WEEK-AT-A-GLANCE

Monday:	**work, take son to dentist**
Tuesday:	**work, son's soccer practice, choir practice**
Wednesday:	**off work, doctor, grocery store**
Thursday:	**work, take son to soccer game**
Friday:	**work, home**
Saturday:	**work, soccer practice**
Sunday:	**church, family reunion**
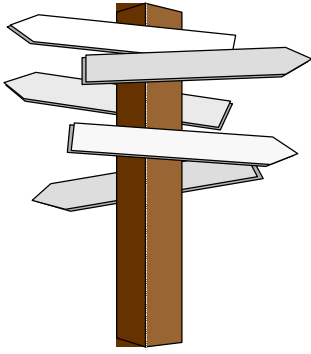
WHERE WE'VE BEEN, WHERE WE'RE GOING

Points

✓ Moving from a program centered approach to a person centered approach is more than using new language

✓ We, as providers of supports and services for individuals with disabilities, are in the process of learning how to respect that the person or family should be setting the course of our actions

✓ Person centered planning is a commitment
> ➤ to break barriers for individuals to be a part of community life;
> ➤ to change policies;
> ➤ to change practices;
> ➤ to change the way we think;
> ➤ to give up control;
> ➤ to actively listen and do;
> ➤ and to demonstrate respect for the person or family, in working with either, to support the vision of the person; of the family for their child
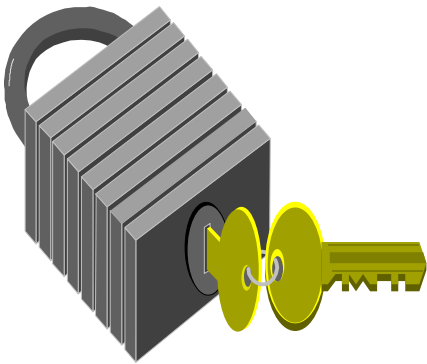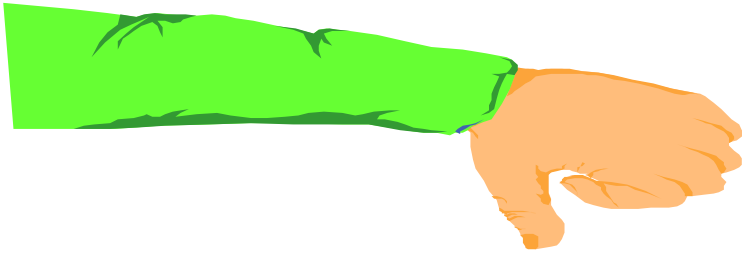
PERSON-CENTERED LANGUAGE

✓ **Language which communicates information about a person, in easily understood, non-clinical, non-"disability speak" words**

✓ **Is the use of plain, simple language**

✓ **Gets rid of words that only human service and medical personnel know**

- **Walks vs. Ambulates**
- **Doesn't talk using words/talks vs. Non-verbal or verbal**
- **Paralyzed on the right side vs. Has right hemiparesis**

These words belong in a medical setting, such as a hospital; not in people's homes and in their lives within the community

✓ **Language which focuses on the person, and not the clinical labels and reputation**

- Gets loud when he is angry <u>vs.</u> verbally aggressive
- Decides he doesn't want to do things sometimes <u>vs</u>. non-compliant
- Is interested in other things <u>vs</u>. off-task

✓ **Language which is always PEOPLE FIRST**
  - **People with disabilities**
  - **A person with mental illness**
  - **A young man with autism**
  - **A woman with a brain injury**

✓ **Language which is respectful of the person and any issues present**

✓ **Language which does not group people by their labels**
  - **The retarded**
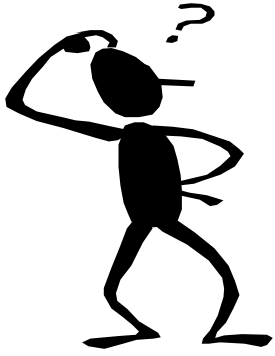 - **The disabled**

Rephrasing

1.　　Mary is a 24 year old moderately retarded Downs female

2.　　Lisa goes off task at her vocational placement

3.　　Robert is an elderly stroke victim

4.　　Let Mary walk to the park by herself

5.　　Joe is a quad and total care client

6.　　Sue is non-compliant with her personal hygiene program

7.　　Staff did Ruth's meds and put her to bed

8.　　Darryl should be allowed time alone when he needs it

9.　I fed Grace and gave her a bath

10.　　Mother tube-feeds at 8:00

11.　　When instructed to do so, John will independently vacuum his floor for 5 consecutive sessions.

12.　　When instructed to do so, Beth will brush her teeth with 100% independence for 5 consecutive sessions by 01-31-02.
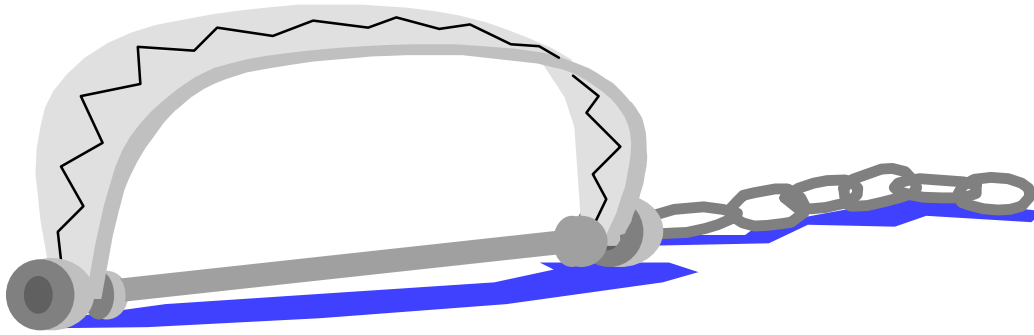
THE REPUTATION TRAP...A REAL BEAR OF A TRAP

| Names or # Committing Offense	Offence: Official Label	Consequence of Behavior
	Eloping	
	Non-compliant	
	Off-task	
	Verbally Aggressive	
	Alcoholic	
	Property destruction	
	Physically Aggressive	
	Criminal	
	Steals Food	
	Pyromaniac	

1. How many of you have ever just had to get away for a while?
2. How many of you have avoided work – either at home or at work?
3. How many of you will be doing something at home and start doing something else before you have finished what was started. Or you start talking to someone at work when you are supposed to be writing notes?
4. How many of you have ever lost your temper and argued with someone?
5. How many of you have ever had a drink?
6. How many of you have ever broken anything in anger – go back to your childhood?
7. How many of you have ever hit someone or bitten someone in anger – go back to your childhood.
8. How many of you have ever failed to stop at a stop sign or have exceeded the speed limit?
9. How many of you have ever, just gone off your diet for a while – having just that one piece of cake or that melted chocolate over ice cream?
10. How many of you have ever deliberately set fire to a building, just to enjoy the flames and the chaos?

What Makes Sense….What Doesn't Make Sense

➢ **Life events, practices or routines that make perfect sense to one person, may make no sense to someone else**

➢ **Often, people with disabilities are asked to live someone else's routine because of where they live or who supports them**

➢ **People with disabilities are often asked to live a routine for staff convenience**

➢ **Other's perspectives can be noted but not imposed on people who are receiving supports**

➢ **It makes sense not to isolate a person with a disability, but to identify and involve the people, whom the person cares about, in his life**

PEOPLE MAP

HOME & SUPPORTS

FAMILY

FRIENDS
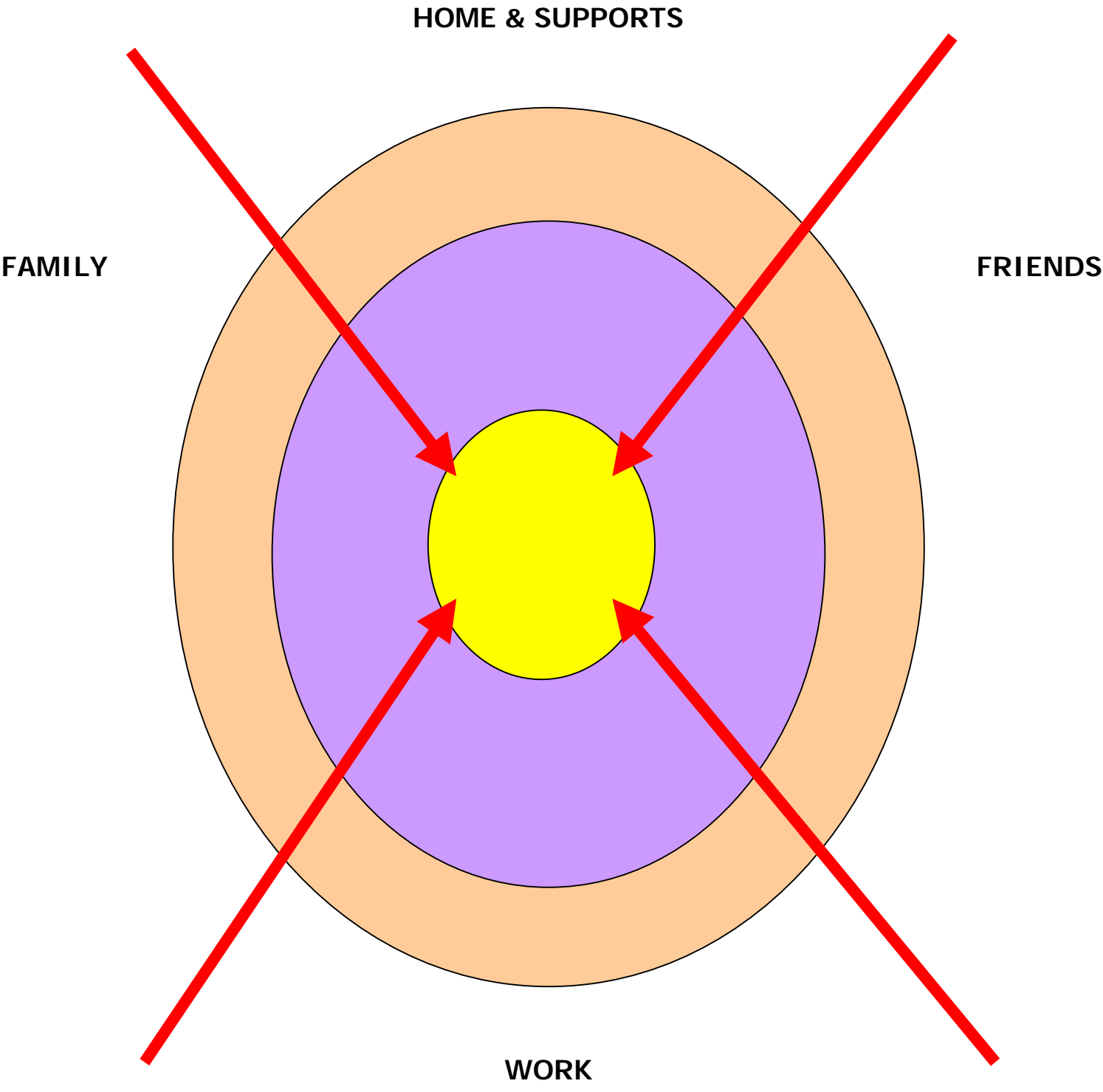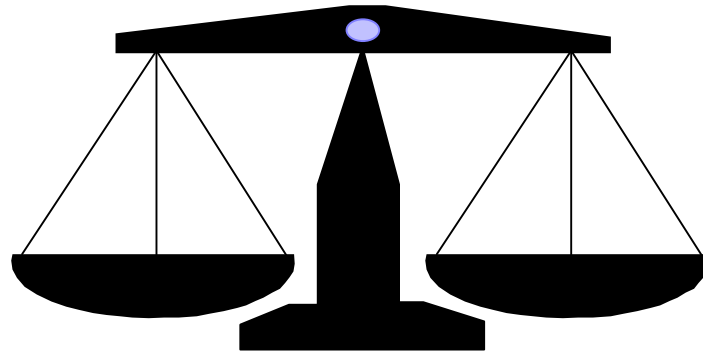
WORK

Balance

Balance

Learning about what is important to the person regarding........

Work

Spiritual Health

Culture

Mental Health

Community Life

Medical Health

Relationships

Driving Me Crazy

➢ **Helping to develop a good plan, based upon what the person wants his/her life to be like, is making a kind of promise and that one is better off not doing any plan than doing a plan where there is no commitment to implement what has been learned**

➢ **Much of the challenging behavior that people in the service system exhibit is explained by this exercise**

➢ **That we need to be sensitive to the behavior/emotions of the people we support who have had plans done that were not implemented**

➢ **A person centered plan is a promise and that if developed but not implemented represents a betrayal of trust**

➢ **An entire constellation of behaviors and symptoms, including hitting other people, breaking things, withdrawal, and being desperate to please, may be a response to years of not being listened to and being powerless**

A SHARED WALK

➢ **The plan, itself is not an outcome**

➢ **And, the process of planning doesn't change a person's life**

➢ **What is important is that the person begins to live the type of life he sees for himself**

➢ **He does this with others (staff person, sister, friend, cousin, neighbor, etc.) around to help with support– they need to be people who know him and like him**

➢ **(I don't want someone who doesn't like me to make plans for my life)**

➢ **Making the plan work involves**
- *listening to the person, "listening" to the person's behavior and trying to understand what the person wants*
- *seeing the whole person*
- *planning*
- *trying to make the plans work*
- *stopping to see how it's working*
- *if it's not working, seeing what has been missed – trying to listen and understand in a different way*
- *making changes,*
- *working to solve problems that might keep the person from reaching his goals*

CHANGE

Questions	10 Years Ago	5 Years Ago	This Year
1. Where do you work?			
2. Where do you live?			
3. Who is your partner?			
4. Who are your best friends?			
5. What kind of car do you have?			
6. What sport do you play?			
7. What church do you attend?			
8. Where do your parents live?			
9. What do you enjoy doing when you are not working?			
10. Where are you going on vacation?			
11. What kind of health do you have?			
12. What is your main worry?			
13. What gives you the greatest pleasure?			
14. What causes you the most pain?			
15. How many children do you have?			
16. How many pets do you have?			

17. Who chooses your doctor?			
18. Who chooses your dentist?			
19. Who decides what routines you will follow?			
20. Who decides what you will do at Christmas? On your birthday? At Thanksgiving?			
21. Who decides what you will go on a daily basis?			
22. Who decides what you will do for fun?			
23. Who decides with whom you do fun things?			
24. Who decides what you will eat?			
25. Who decides what chores you will do?			
26. Who decides what you will learn?			
27. Who decides with whom you will live?			

CHANGE

John. Age 43. Is a person who receives supports 24 hours a day.

Questions	10 Years Ago	5 Years Ago	This Year
1. Where do you work?	Attended "school"/ workshop	Worked at a plant	Attended workshop
2. Where do you live?	Institution	Institution	Group Home #1
3. Who is your partner?	Assigned roommate	Assigned roommate	Assigned house mates
4. Who are your best friends?	Mary (support person)	Teresa (support person)	Paula (support person)
5. What kind of car do you have?	No car	No car	No car
6. What sport do you play?	*Watch* baseball	*Watch* baseball	*Watch* baseball
7. What church do you attend?	First Baptist	First Baptist	Whichever Paula takes me to
8. Where do your parents live?	Jefferson	Jefferson (Dad died)	Jefferson
9. What do you enjoy doing when you are not working?	Talking with staff	Going to the beach/church	Talking with staff
10. Where are you going on vacation?	Camp	Beach	None planned
11. What kind of	Good – only	Good – only	Good – only

health do you have?	some problems with dandruff, cavities and athlete's foot…Maybe gaining some weight	some problems with dandruff, cavities and athlete's foot…Maybe gaining some weight	some problems with dandruff, cavities and athlete's foot…Maybe gaining some weight
12. What is your main worry?	Not seeing my family	Not seeing my family	Having to go to the workshop
13. What gives you the greatest pleasure?	Seeing my family	Seeing my family	Seeing my family
14. What causes you the most pain?	When people talk about what I'm doing wrong	Not seeing my family (planning was based upon his preferences)	When people talk about what I'm doing wrong
15. How many children do you have?	None	None	None
16. How many pets do you have?	None	None	None
17. Who chooses your doctor?	See one at institution	See one at institution	Agency chooses for all of us
18. Who chooses your dentist?	See one at institution	See one at institution	Agency chooses for all of us
19. Who decides	Institution	Institution &	Agency

what routines you will follow?		now work around job & church	
20. Who decides what you will do at Christmas? On your birthday? At Thanksgiving?	Institution	Institution & family when they ask to see me	Agency & family when they let me come home
21. Who decides where you will go on a daily basis?	Institution	Institution	Agency
22. Who decides what you will do for fun?	Institution	Institution	Agency
23. Who decides with whom you do fun things?	Institution	Institution	Agency
24. Who decides what you will eat?	Institution	Institution	Agency, except when the group goes out to eat
25. Who decides what chores you will do?	Institution	Institution	Agency
26. Who decides what you will learn?	Institution	Institution, but can make some decisions	Agency
27. Who decides with whom you live?	Institution	Institution	Agency

ATTACHMENTS
FORMS

CAP-MR/DD Elements for Person Centered Planning (Required Form)

❑ Understand the importance of language that demonstrates respect, shared control, and use of "person first" language.

❑ Understand the basic philosophy of person and family centered planning.

❑ Understand the difference between traditional planning methods and use of the person centered model.

❑ Understand the methods for gathering information about the person.

❑ Understand support staff roles and responsibilities in planning and implementing a plan with a person or with a family.

❑ Understand that people change, therefore their plan changes.

The signatures below verify that training in the elements indicated above has been completed and the direct care staff understands his/her responsibilities relating to the elements.

_____   _____
Signature of direct care staff   Signature of trainer

_____   _____
            Date   Date

DEMONSTRATION OF COMPETENCIES FOR ELEMENTS OF PERSON CENTERED PLANNING (Optional for use)

ELEMENT	DEMONSTRATED COMPETENCY	DATES OBSERVED
❑ Understand the importance of language that demonstrates respect, shared control, and use of "person first" language.	❑ Support staff takes time to listen to the person ❑ Support staff responds, in action, to requests the person may make ❑ Support staff does not try to control the relationship ❑ Support staff does not use words such as, 'let, allow, instruct' when talking with the person – does not dictate actions to the person ❑ Support staff uses the person first, disability second language when describing a person and the disability the person has ❑ Support staff does not use labels to describe the person's behavior, e.g. 'off-task', aggressive, non-compliant, etc., either in communicating with the person, with others or in notes. Staff communicate what happened and what the person's response was ❑ Support staff does not talk about sensitive issues, relating to the person, around others ❑ Support staff does not share information about the person without the person's consent ❑ Support staff knows and respects the person's *Rights*.	❑
❑ Understand the basic philosophy of person and family centered planning.	❑ Support staff demonstrates that the focus is on the person first.	❑
❑ Understand the difference	❑ Support staff does not speak in a deficit-based way (what the person does wrong,	❑

Agency Name: _____
Agency Address: _____
_____
Agency Phone: _____
Agency Fax: _____
Agency Contact: _____
Contact E-Mail: _____
Date Competency
Form Completed: _____
Completed for: _____
Completed by: _____

DEMONSTRATION OF COMPETENCIES FOR ELEMENTS OF PERSON CENTERED PLANNING (Optional for use)

ELEMENT	DEMONSTRATED COMPETENCY	DATES OBSERVED
between traditional planning methods and use of the person centered model.	cannot do). ❑ Support staff do not decide what the person wants to do, but finds out from the person what he/she wants to do	
❑ Understand the methods for gathering information about the person.	❑ Support staff ask the person questions about himself, his past, about his preferences, his dreams, about how he wants friends and family involved in his life ❑ For those who do not communicate with words, support staff learn what the person likes/does not like, wants to do/doesn't want to do and shares that information with the person's team of supports ❑ When working with families, support staff take time to listen to family members input; to listen to how the family member wants his/her child supported; to ask questions of the family members ❑ Support staff, with permission from the person, talk to the person's friends and family members, asking questions about the things the person enjoys doing, what things to avoid, favored routines and rituals, what to avoid to help the person experience good days, about the person's dreams ❑ When the person is unable to relay information, the staff person assists in describing health issues and concerns to planning team members/with this person's circle of support ❑ With the person's permission, support staff shares information about reactions of the individual to his environment (home, work, community) in order to assure that things the person likes/enjoys are included as a part of the person's routines; in order to	❑

Agency Name: _____
Agency Address: _____
_____
Agency Phone: _____
Agency Fax: _____
Agency Contact: _____
Contact E-Mail: _____
Date Competency Form Completed: _____
Completed for: _____
Completed by: _____

Form 2
R4/26/01

DEMONSTRATION OF COMPETENCIES FOR ELEMENTS OF PERSON CENTERED PLANNING (Optional for use)

ELEMENT	DEMONSTRATED COMPETENCY	DATES OBSERVED
	avoid imposing routines that are negative, upon the person	
❑ Understand support staff roles and responsibilities in planning and implementing a plan with a person or with a family.	❑ Support staff does not try to complete objectives when the person does not want to work on objectives ❑ Support staff observes when the person is having a stressful time and does not push the issue of completion of tasks, but shares the task when the person is able to cope with addressing the task ❑ The support staff does not change a person's routine for his/her own convenience ❑ The support staff talks about what is important to the person, not about the things that are wrong with the person	❑
❑ Understand that people change, therefore their plan changes.	❑ The support staff knows change is good and that change occurs as the person's situations in life change. This is demonstrated by staff willingness to share new observations/new information and to be a willing partner in assisting the person, where necessary, to make good changes happen	❑

Agency Name: _____

Agency Address: _____

_____

Agency Phone: _____

Agency Fax: _____

Agency Contact: _____

Contact E-Mail: _____

Date Competency Form Completed: _____

Completed for: _____

Completed by: _____

AGENCY CHECKLIST FOR ASSESSING PRESENCE OF ELEMENTS THAT SUPPORT PERSONAL OUTCOMES
(Optional for use)

CONSIDERATIONS:
- The existence of evidence does not necessarily equate with the presence of an adequate array of supports for a particular area. Supports must be specifically applicable and useful for the individual. Professional judgement will be necessary in assessing and determining the comprehensiveness and adequacy of the identified supports based on the specific needs and circumstances of the person
- It is not expected nor realistic that evidence of supports will be present (or if present, adequate) for each area.

In order to determine if your agency has elements that support personal outcomes, part of the evidence needs to include a sample of the individuals receiving services from your agency. Meet with each person that is a part of the sample and ask questions relating to the item on the checklist, but in terms that are easily understood. Each time you use this evaluation, use a different sample of individuals.

QUESTION	EVIDENCE OF PRESENCE OF ELEMENTS THAT SUPPORT PERSONAL OUTCOMES
1. How does this agency show recognition that an individual receiving supports selects his/her own goals? (That goals are developed in partnership with an individual, and not exclusively by team members?)	❑
2. During the past year has the agency recognized and celebrated achievement of the attainment of goals with an individual?	❑
3. What evidence is there present to show that the individual chooses with whom he/she lives?	❑
4. What evidence is there that the individual chooses where he/she wants to live?	❑
5. What evidence is present to indicate that the individual chooses where to work and that his/her choice is based on an array of all options specifically available in the surrounding community? (NOTE: retirement or full time school participation can be substituted for work, however the same criteria for evidence apply.)	❑
6. Is the agency aware of, sensitive to, and respectful of the multiple and varied privacy needs of the individual?	❑
7. Is evidence present to show agency awareness and respect of confidentiality desires of the person?	❑
8. Does the agency provide education about confidentiality in a manner specific to the needs of the person?	❑
9. Is evidence present to indicate that the agency provides education to the individual (and guardian if applicable) about consent for release of **verbal or**	❑

AGENCY CHECKLIST FOR ASSESSING PRESENCE OF ELEMENTS THAT SUPPORT PERSONAL OUTCOMES
(Optional for use)

CONSIDERATIONS:
- The existence of evidence does not necessarily equate with the presence of an adequate array of supports for a particular area. Supports must be specifically applicable and useful for the individual. Professional judgement will be necessary in assessing and determining the comprehensiveness and adequacy of the identified supports based on the specific needs and circumstances of the person
- It is not expected nor realistic that evidence of supports will be present (or if present, adequate) for each area.

In order to determine if your agency has elements that support personal outcomes, part of the evidence needs to include a sample of the individuals receiving services from your agency. Meet with each person that is a part of the sample and ask questions relating to the item on the checklist, but in terms that are easily understood. Each time you use this evaluation, use a different sample of individuals.

QUESTION	EVIDENCE OF PRESENCE OF ELEMENTS THAT SUPPORT PERSONAL OUTCOMES
written information?	
10. Is the agency supporting the individual to have full access to all parts of his/her home, **including use of equipment**?	❑
11. Is the agency supporting the individual to have full access to his/her work environment?	❑
12. Based on the desires of the individual (with the expectation that the person is aware of all options), is the person supported to live and be part of environments (physical and social) that are integrated **with people who do not have disabilities**?	❑
13. Is the person clearly satisfied with the amount, type and frequency of his/her participation in community activities?	❑
14. Based on the desires of the individual (with the expectation that the person is aware of options), is the person interacting (or being assisted to interact) with members of the surrounding, integrated community? In addition, is the person clearly satisfied with the amount, type and frequency of his/her interaction with other people?	❑
15. Does the agency assist and support this person to know and experience a variety of social roles of the integrated community?	❑
16. Does the agency assist and support the person to fill desired social roles, and manage the associated responsibilities?	❑
17. Does this person have non-paid friends, and is the agency specifically aware of, and supportive of the	❑

AGENCY CHECKLIST FOR ASSESSING PRESENCE OF ELEMENTS THAT SUPPORT PERSONAL OUTCOMES
(Optional for use)

CONSIDERATIONS:
- The existence of evidence does not necessarily equate with the presence of an adequate array of supports for a particular area. Supports must be specifically applicable and useful for the individual. Professional judgement will be necessary in assessing and determining the comprehensiveness and adequacy of the identified supports based on the specific needs and circumstances of the person
- It is not expected nor realistic that evidence of supports will be present (or if present, adequate) for each area.

In order to determine if your agency has elements that support personal outcomes, part of the evidence needs to include a sample of the individuals receiving services from your agency. Meet with each person that is a part of the sample and ask questions relating to the item on the checklist, but in terms that are easily understood. Each time you use this evaluation, use a different sample of individuals.

QUESTION	EVIDENCE OF PRESENCE OF ELEMENTS THAT SUPPORT PERSONAL OUTCOMES
person's current desire for friendships?	
18. Is the agency clearly aware of intimacy needs of the person (NOTE: these are needs beyond friendship, and may or may not include sexual expression)?	❑
19. Is clear evidence present and that demonstrates active support of the intimacy needs and desires of this person?	❑
20. Do the actions of all involved support staff demonstrate sincere respect for the person to whom they are providing supports? (Expectations for the person's achievement are high, no one draws undue attention to the person's disabilities, staff listens and responds to what the person is saying, the person has meaningful work and activities to do, etc.	❑
21. What evidence suggests that the person does, or does not believe that he/she is respected?	❑
22. What evidence is present to show that the person is aware of a comprehensive range of generic community services?	❑
23. Is the person supported by the agency to access community services based on personal choice (and not driven by the convenience of others)?	❑
24. Is evidence present that the agency actively pursues opinions of the person related to satisfaction of general community services?	❑
25. What evidence is present to show that the person is aware of local MH/DD/SA services?	❑
26. Is the person supported by the agency to exercise choice of services within the local MH/DD/SA	❑

Based on Personal Outcomes developed by
The Council on Quality and Leadership
In Supports for People with Disabilities
Adapted by Chris Egan

AGENCY CHECKLIST FOR ASSESSING PRESENCE OF ELEMENTS THAT SUPPORT PERSONAL OUTCOMES
(Optional for use)

CONSIDERATIONS:
- The existence of evidence does not necessarily equate with the presence of an adequate array of supports for a particular area. Supports must be specifically applicable and useful for the individual. Professional judgement will be necessary in assessing and determining the comprehensiveness and adequacy of the identified supports based on the specific needs and circumstances of the person
- It is not expected nor realistic that evidence of supports will be present (or if present, adequate) for each area.

In order to determine if your agency has elements that support personal outcomes, part of the evidence needs to include a sample of the individuals receiving services from your agency. Meet with each person that is a part of the sample and ask questions relating to the item on the checklist, but in terms that are easily understood. Each time you use this evaluation, use a different sample of individuals.

QUESTION	EVIDENCE OF PRESENCE OF ELEMENTS THAT SUPPORT PERSONAL OUTCOMES
program?	
27. Is evidence present that the agency actively learns about the satisfaction of the person related to all services received including but not limited to services received by the agency such as: case management, psychiatric, psychological, counseling, nursing, etc.?	❑
28. Does the agency actively support the person to maintain family and other long-term natural relationships? Or, if the person is not connected to family does the agency continue to search for and explore for family or historical relationships?	❑
29. Does the agency work toward a balance of support for this person's unique needs related to home, work and community safety (not lacking in necessary supports while being clear about preventing over-support?	❑
30. Is evidence present confirming agency staff knowledge of (human and client) rights?	❑
31. Is evidence present that individualized training has been provided to the individual that is specifically related to his/her desires to learn about and exercise rights?	❑
32. Is evidence present that the agency has specific support in place to assist the individual to exercise the responsibilities associated with his/her rights?	❑
33. Does the individual believe his/her rights are respected, or violated?	❑
34. If applicable, does the agency attempt to facilitate a partnership between the guardian and individual, so	❑

AGENCY CHECKLIST FOR ASSESSING PRESENCE OF ELEMENTS THAT SUPPORT PERSONAL OUTCOMES
(Optional for use)

CONSIDERATIONS:

- **The existence of evidence does not necessarily equate with the presence of an adequate array of supports for a particular area. Supports must be specifically applicable and useful for the individual. Professional judgement will be necessary in assessing and determining the comprehensiveness and adequacy of the identified supports based on the specific needs and circumstances of the person**
- **It is not expected nor realistic that evidence of supports will be present (or if present, adequate) for each area.**

In order to determine if your agency has elements that support personal outcomes, part of the evidence needs to include a sample of the individuals receiving services from your agency. Meet with each person that is a part of the sample and ask questions relating to the item on the checklist, but in terms that are easily understood. Each time you use this evaluation, use a different sample of individuals.

| QUESTION	EVIDENCE OF PRESENCE OF ELEMENTS THAT SUPPORT PERSONAL OUTCOMES
that the guardian is aware of what the person wants and works with him or her to achieve that?	
35. If the person is deemed incompetent, is he or she still involved in the decisions of his/her life?	❏
36. Does the agency have a process to provide safeguards against rights violation(s)?	❏
37. If a rights violation has occurred, what evidence is present to demonstrate resolution and future protection?	❏
38. In the event of a planned restriction (through use of a behavior plan) does the agency demonstrate competence to assist in the development of an individualized time-limited approach?	❏
39. Is evidence present of an objective oversight review process (due process), in which the person can speak or have representation, and understands the nature and reasons for the restriction?	❏
40. Does the agency have a user-friendly, accessible system for the individual to safely communicate a complaint?	❏
41. Is agency staff aware of rules for reporting suspected abuse, neglect, or exploitation?	❏
42. Has the individual been abused, exploited, or neglected?	❏
43. Does the agency employ an effective system for investigating complaints?	❏
44. Does the person indicate that he/she is treated fairly by those who provide support(s)?	❏
45. Does the organization understand the individual's	❏

AGENCY CHECKLIST FOR ASSESSING PRESENCE OF ELEMENTS THAT SUPPORT PERSONAL OUTCOMES
(Optional for use)

CONSIDERATIONS:
- **The existence of evidence does not necessarily equate with the presence of an adequate array of supports for a particular area. Supports must be specifically applicable and useful for the individual. Professional judgement will be necessary in assessing and determining the comprehensiveness and adequacy of the identified supports based on the specific needs and circumstances of the person**
- **It is not expected nor realistic that evidence of supports will be present (or if present, adequate) for each area.**

In order to determine if your agency has elements that support personal outcomes, part of the evidence needs to include a sample of the individuals receiving services from your agency. Meet with each person that is a part of the sample and ask questions relating to the item on the checklist, but in terms that are easily understood. Each time you use this evaluation, use a different sample of individuals.

QUESTION	EVIDENCE OF PRESENCE OF ELEMENTS THAT SUPPORT PERSONAL OUTCOMES
personal perception of what his/her best possible health would be including medical/physical, emotional, psychiatric, etc.?	
46. Is support provided to the individual to receive all necessary medical, physical, psychiatric and emotional supports?	❑
47. Does the agency provide education and support to the individual related to medical concerns, medications and preventative health care?	❑
48. In the event of an emergency, are specific supports present to assist the person to remain safe?	❑
49. Does the agency have insurance, and is the person provided information and support related to various insurance options for protection in the event of an emergency?	❑
50. How does the agency share the balance of control with the person over changes in direction related to services, supports, change in staff or location, etc.?	❑
51. Does the agency demonstrate practices of supporting the individual to evaluate, broadly, satisfaction with general life circumstances?	❑

Form 3
R4/26/01
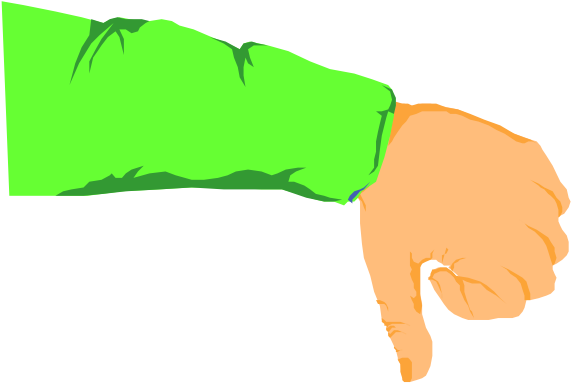
Rephrasing (Instructor's Copy)

(Note: These are only some examples of how these sentences can be rephrased. Encourage appropriate originality.)

1. *Mary is a 24 year old moderately retarded Downs female*
   Mary is 24 years old.
   Mary, who is 24 years old and is a female, has Down's Syndrome.

2. *Lisa goes off task at her vocational placement*
   Lisa daydreams, sometimes, at work.
   Lisa is very interested in what is going on around her, at work.

3. *Robert is an elderly stroke victim*
   Robert had a stroke.
   Robert, an older gentleman, had a stroke.

4. *Let Mary walk to the park by herself*
   Mary likes to walk to the park alone.

5. *Joe is a quad and total care client*
   Joe's arms and legs are paralyzed. Someone assists him in doing the things he wants to do and in the things he needs to do.

6. *Sue is non-compliant with her personal hygiene program*
   Sue sometimes decides not to take a bath or brush her teeth. Sue decides when she wants to take care of her own hygiene needs.

7. *Staff did Ruth's meds and put her to bed*
   With staff assistance, Ruth took her medication and went to bed.

8. *Darryl should be allowed time alone when he needs it*
   Darryl decides when he needs to get away from other people. Darryl enjoys time alone.

9. *I fed Grace and gave her a bath*
   Grace ate and took her bath.
   With some help, Grace ate and took her bath.

10. *Mother tube-feeds at 8:00*
    At 8:00, the Mother helps her child to eat.
    At 8:00, the child eats, with Mother's help.

11. *When instructed to do so, John will independently vacuum his floor for 5 consecutive sessions*
    John vacuums his floor by himself, when asked to do so. He no longer needs help to do this.

12. *When instructed to do so, Beth will brush her teeth with 100% independence for 5 consecutive sessions by 01-31-02*
    Beth brushes her teeth by herself, when asked to do so. She no longer needs help in this area. (If doing this for billing, can have a column for projected completion date.)

ATTACHMENTS
ARTICLE

Person centered planning, should we do it with everyone?
Michael W. Smull

Over the past five years person centered planning has undergone a transformation. It has gone from something mysterious that only a few dedicated and skilled people did to something where nearly everyone says "I have been doing person centered planning for years." Person centered planning and person centered services have become trendy. It has become a litmus test for being politically correct. Any activity where people are asked what they like or want is seen as person centered. Further, states, regions, and counties are beginning to require (or to consider requiring) person centered planning for everyone receiving services or entering services.

From my travels (and from the materials that get sent to me) I have learned that many of the alleged person centered plans and person centered services are not person centered at all. Plans are being written where what is important to those who provide services is written as if it were important to the person receiving services, that abuse the "voice" of the person (e.g. "I must be reinstated"). People whose only real dream is to get out of the institution they live in have plans that say that it is their dream to live by themselves in a house in suburbia. People are asked questions where they do not have the life experiences necessary to give an informed answer. Questions are asked that have the answer built in. Equally troubling are the honest plans that are not implemented. Over and over again I hear of people who tell us things such as desperately wanting a new roommate who never get one. Much of what is being done represents no real change in practice. It is business as usual masquerading as being person centered.

Person centered planning is a means not an end
A person centered plan is a means not an end. The life that the person wants is the outcome, not the plan that describes it. Person centered planning is a process of learning how a person wants to live and then describing what needs to be done to help the person move toward that life. It is a description of where the person wants their life to go and what needs to be done (and what needs to be maintained) to get there. Good plans are rooted in what is important to the person while taking into account all of the other factors that impact on the person's life – the effects of the disability, the views of those who care about (and know) the person, and the opportunities as well as the limitations presented by the need for public funding.

A person centered plan reflects a process:

> That is respectful of the person with the disability, the family, and those who support the individual;

Where the time and effort necessary is spent to be sure that the "voice" of the person with the disability is heard regardless of the severity and nature of the disability; and

Where there is a focus on learning what is important to the person in how he or she wants to live, what is important to those who love the person, and any issues of health and safety (from the perspective of the person).

The resulting plan is a written description of what is important to the person, how any issues of health or safely must be addressed, and what needs to happen to support the person in their desired life. The plan cannot be separated from the process. A compromised process produces a compromised plan.

Beyond these common elements there is considerable variation. Some of the better known formal processes include: personal futures planning; PATH; essential lifestyle planning; individual service design; 24 hour planning; and whole life planning. Additionally there are a host of processes that have been developed locally. These local processes are often unnamed and usually are a blend of the better known processes. However, the label of the process is not an indicator of the utility or integrity of the plan. When done well, what unites all of these efforts is a commitment to learning what is important to people and a commitment to implementing what was learned. They all require partnerships between: the person; those who know the person; those who develop the plan; and those who implement the plan.

What has been learned
Where careful planning and implementation have been done we have learned that:

When we listen with skill and respect, we can learn what is important to each person regardless of severity of disability;

Planning is a continuous effort, what people want tomorrow is different from what they want today;

Growth and learning occur naturally when people have the opportunities that they want, opportunities that make sense in the context of what is important to them;

Providing structure inside those opportunities helps people with severe disabilities access and learn more from those opportunities;

Most of the behaviors that we have labeled as non-compliance, as challenging, or as problem behaviors, go away when what is important to people is present;

Regardless of severity of disability, people are able to take positive control over their lives as we learn to listen and trust develops; and

Building community, a network of self-sustaining reciprocal relationships, occurs but it usually takes years not months.

We also have learned that while what is most important to people is modest, implementation is affordable only if we change the way we do business. Unless we begin to fund people rather than capacity, individuals rather than houses, we cannot afford to implement plans where people are asking to change who they live with or what they do. We have learned that it is our own structures that are the barriers and that many of the reports of high costs reflect the rigidity of our responses.

Person centered planning is also a promise

Shifting a system cannot be done by fiat and it cannot be done overnight. It requires the development of capacity, changing the structures that define where the system is going and what it should pay attention to, and it requires political courage and political capital. Some of the ingredients needed to change the system are:

Training in person centered thinking for all of the people involved in planning and implementation;

Requiring that those who do the plans demonstrate competency in person centered planning and that some of their plans be periodically reviewed;

Training for those who license and inspect, and requiring that they be able to determine that plans meet criteria and that the plans are being implemented;

Changing the rules for services and requirements for funding so that they support person centered planning and implementation;

Support (training and technical assistance) for agencies that want to change their practices and structures;

Helping people with disabilities and their families build community before they are desperate, while families have the energy and resources to form a partnership; and

Leaders who understand what real person centered planning is, the changes needed for their implementation, and a willingness to build support while defending the changes from those who feel threatened.

At its core, developing and implementing person centered plans is about shifting power and control. It is about sharing control with the people supported and their families. To many people this is an opportunity to be embraced but to others it represents a serious loss of power. Person centered planning should be done with everyone only where there is the willingness to make the investments and changes necessary. However, those who lead must also sustain the change in the face of resistance and attacks. Those who wish to initiate the change need to develop the strategies necessary to sustain the change. In learning what is important to people we make an implicit promise to act on what we have learned. We should not make the promise unless we believe we can keep it.

College Park, Maryland
November, 1996